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ABSTRACT

The fourth of 16 booklets designed for use in an Open University course about education for handicapped children in the United Kingdom, this document focuses on family life, particularly in families with severely handicapped children. Parents' reactions to the initial diagnosis of their child's handicapping condition are discussed, as well as the practical problems and social isolation facing families with handicapped children, and subsequent stresses within the family system. Family resources, including practical and financial help, short term care, advisory and teaching services, and self-help groups for parents are described. Parent-school relationships are explored, as are areas of responsibility between parents and professionals. Reading assignments and activities are offered throughout. (CL)

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The Open University
Educational Studies: A Second Level Course
Special Needs in Education

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The Open University
Educational Studies: A Second Level Course
E241 Special Needs in Education

Unit 3
Family views

Prepared by David Thomas and Will Swann
for the Course Team

The Open University Press

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Contents

	Note on reading	4
	Broadcasts	4
1	**Introduction**	5
2	**Caring for handicapped children**	5
	The first shock: the identification of a handicapped child	5
	The long struggle: the consequences of a handicapped child	11
	Practical problems	11
	Teaching children to cope for themselves	13
	Social isolation	14
	Do handicapped children produce abnormal families?	15
	Services for families	19
	Practical and financial help	20
	Short-term care	22
	Advisory and teaching services	23
	Parents' needs and professional services	25
	Self help	26
3	**Schools and parents**	27
	Parents and ordinary schools	28
	Parents and special schooling	29
	Parental power and special education	31
4	**Parents and professionals: whose responsibility?**	32
	Ideals and reality	34
	References	38
	Acknowledgements	39

Note on reading

Set reading

The readings for this unit are to be found in:

SWANN, W. (ed.) (1981) *The Practice of Special Education*, Oxford, Basil Blackwell/The Open University Press (the Reader). They are:

BOOTH, T. A. (1978) 'From normal baby to handicapped child: unravelling the idea of subnormality in families of mentally handicapped children' (Reading 4.2).

GLIEDMAN, J. and ROTH, W. (1980) 'Parents and professionals' (Reading 4.1).

The case studies for this unit are to be found in:

BOOTH, A. J. and STATHAM, J. (1982) *The Nature of Special Education*, London, Croom Helm/The Open University Press. They are:

'Caring for a mentally handicapped child: the daily routine' (Case study 16).

'Help yourselves: support services for parents of a severely handicapped boy' (Case study 17).

'There'll never be a time when I'm young and free' (Case study 13).

'The Wilson family' (Case study 15).

'A community worker in a special school' (Case study 25).

'Parent participation: setting up a special unit in a private school' (Case study 20).

'Professional "help": the Taylor family' (Case study 12).

Further reading

If you wish to read more on subjects discussed in this unit, we recommend the following:

BALDWIN, S. (1977) *Disabled Children—Counting the Costs*, London, The Disability Alliance.

BRADSHAW, J. (1980) *The Family Fund: an initiative in social policy*, London, Routledge and Kegan Paul.

GREGORY, S. (1976) *The Deaf Child and his Family*, London, George Allen and Unwin.

MCCORMACK, M. (1978) *A Mentally Handicapped Child in the Family: a guide for parents*, London, Constable.

PUGH, G. (1981) *Parents as Partners*, London, National Children's Bureau.

STONE, J. and TAYLOR, F. (1977) *A Handbook for Parents with a Handicapped Child*, London, Arrow Books.

Broadcasts

Radio programme 2 is part of this unit, and you should read the broadcast notes associated with it before listening to it.

1 Introduction

1.1 Mary McCormack, whose son Patrick is mentally handicapped, has this to say about professionals' knowledge and understanding of parents' problems:

> There is, to put it mildly, some antipathy between parents and the professionals—doctors, social workers, teachers, nurses—who help them care for their handicapped child and at times take over the responsibility. A feeling by parents that with the best training and the best will in the world, professionals cannot really understand their child and their problems.
>
> (McCormack, 1978, p. 181)

In this unit we are going to look at what problems and difficulties parents face when they have a handicapped child. We shall discuss the emotional, financial and practical burdens on families, often using parents' own words, as they can tell their own story much more eloquently than anyone else. Then we shall look at whether or not professionals and services, designed to help families, do so, or whether they are in some circumstances an added burden. Throughout this unit, we hope to give you some idea of what it is like to be a parent with a handicapped child.

1.2 The field is so big and so diverse that we have inevitably had to restrict ourselves in certain ways. We shall concentrate on families with children who have severe physical, mental and sensory handicaps, most of which appeared early in childhood. Children with problems that develop or emerge later and are less seriously handicapping, such as children who are classed as ESN(M) or maladjusted, are not dealt with in depth, as Unit 7 will concentrate on these children rather more. It is very important that you don't generalize from the experiences of one family and one type of handicap to all others, since, as you'll see from even the limited number of examples given in this unit, there is enormous variation in the needs and characteristics of all families.

1.3 In section 2 we look at how families care for handicapped children and the problems they face, starting with some of the events that surround the birth of a handicapped child, and what happens when a child is identified as mentally handicapped after a year or two of apparently normal life. We then look at the problems that families have coping with handicapped children and the effects such problems can have on other members of the family: then, in the remainder of section 2, we examine some of the services available to families and the extent to which these meet families' expressed needs.

1.4 In section 3 we look at the contacts that parents have with the education system. In the first part we compare contacts that parents of normal children have with their teachers with the contacts between teachers and handicapped children's parents; in the second part we look at parents' rights in education and at the power they can exert over the authorities. These discussions allow us to evaluate to what degree there is a partnership between parents and schools.

1.5 In the last section, we bring together some of the more general issues in the unit, to study in more depth the relationships between parents and professionals, and to consider briefly what the rights and responsibilities of each group are.

2 Caring for handicapped children

The first shock: the identification of a handicapped child

2.1 To be told your child is severely handicapped is a great shock. It must be nearly impossible for someone who has not been in that situation to understand what it is like. How and when the parents are told varies for different disabilities. Some children's defects are apparent at or shortly after birth: this is true of Down's Syndrome and spina bifida. But many other parents go through a number of years of more or less normal life

with their child before they discover something is wrong. Children with some forms of muscular dystrophy don't begin to show signs of disability until adolescence; it may be two years before parents suspect their child has a hearing loss. How these events are handled is of crucial importance to the immediate and future well-being of both parents and children.

2.2 Here is an account by one mother who gave birth to a child with Down's Syndrome. She had had several miscarriages before giving birth at 38:

> Melanie, my little girl, was born about 5 o'clock that evening. I had a bit of a rough time and had stitches the same as I had on my other babies.
>
> That was all past now. I had my little girl and everything had been worth it. I thought of my husband, what he'd say. I was absolutely thrilled to bits. It was funny really, about 10 minutes after I had the baby my husband 'phoned and heard about Melanie. My neighbours said he was skipping in the street telling everyone I had a girl.
>
> Everybody seemed to be milling around the labour ward. I saw a doctor looking at Melanie in her cot and she came and said my little girl was lovely. At the time I thought it was funny there being a doctor there but I passed it off as routine.
>
> I went up to the ward as it was by then nearly visiting time. I couldn't wait see my husband.
>
> They usually bring your baby with you from the labour ward but I was told they were really rushed off their feet. As soon as they washed baby they would bring her to see me.
>
> I can't tell you what I actually thought at the time I was so tired and I thought she won't be long.
>
> My husband came to see me with my mother. He came up the ward with smiles beaming all over his face. I remember him saying, 'We've cracked it, love, at last.'
>
> Melanie hadn't been brought to me. It was half way through visiting, I asked the nurse could my husband see baby she said she would take him up to see baby before he went home.
>
> My husband saw Melanie and came back down to tell me she was lovely and looked the same born as our other children, he went home and time passed. At last they brought me Melanie, she was lovely. She had scratched her face, her nails were that long but to me she was gorgeous. I had a good night's sleep at last.
>
> Melanie slept all night. The next day I felt as if I was walking on air. The doctor came to see me and we was talking about me being sterilized. I asked him when would he be doing the operation and he said he would come back and see me about it again. When I first went to ante-natal I had asked could I have this done. My doctor looked my notes up and reckoned with all my miscarriages this would be my seventh pregnancy so he said yes, he would do it after the baby was born.
>
> Well the day wore on and I felt I was the happiest mum in all the world. Melanie was good and just taking glucose water. I intended to feed her myself like I had done my other babies.
>
> I was on the way to the bathroom to get myself prettied up and have a bath before visiting at seven o'clock. I remember it was round about five o'clock.
>
> On my way to the bathroom the sister came to me and said, 'Mrs. J, we are just taking Melanie to the nursery, doctor wants to see her'.
>
> I just passed this off as routine and carried on to the bathroom for my bath. I was really enjoying my first bath after having Melanie. I felt very happy at the thought that it was all over at last.
>
> There came a knock on the door and sister popped her head round to say doctor wanted to see me.
>
> I knew then there was something wrong, then I jumped out of the bath not bothering to dry myself or get dressed. I just put my dressing gown on, and dashed out to see doctor.
>
> There was three doctors round my bed and sister. I said, 'What is wrong?' The specialist spoke to me, 'I've got to tell you your little girl won't be like your other children, she will be a bit backward and she will need all the extra love and understanding you can give her.' I don't know how the word 'mongol' came out, I don't know whether I said it or the doctor did. All I know at that moment was the roof had caved in on me. I went a bit hysterical crying, 'There's nothing wrong with her if you're going off her eyes the heavy lids, all my other children

were born like that and my husband's eyes are like that'. I couldn't think, I'd gone numb all over. The doctor told me to get in bed. It was only then I realised I was wet through standing in a puddle of water. I wasn't dressed, I just didn't care. Doctor gave me Melanie then I was in bed rocking her, loving her and out loud I was saying 'I'm sorry, I'm sorry. Oh God it's not true,' but deep down I knew it was. I was fighting for them to say they had made a mistake. It can't happen to me, it only happens to other people. God wouldn't let it happen to me.

They drew the curtains round my bed and the doctor put his arm round my shoulder and he said, 'Well, if you think she looks like your husband it might well be she's taking after him,' but all the time I knew he was sort of shaking his head. I said, 'Tell me, what makes you think she is a mongol?' Looking at her honestly I couldn't see a thing wrong with her.

He started to explain. 'You see their muscles are very floppy,' and he demonstrated this by lifting Melanie's arm up and letting it drop. As you know, a baby can grip your two fingers and by using their strength they can lift themselves up with a grip like steel. I've had this demonstrated to me many a time on my other babies by the midwives, but Melanie couldn't do this. I went mad crying. I couldn't help myself, it was a sort of despair crying. I heard the doctor saying, 'Tell your husband I want to see him in the morning,' then they left me alone, holding Melanie to me. I was crying, nothing mattered, I wasn't aware there was anybody else in the ward. I knew I had to tell my husband. I was just longing for him to be there.

I got out of bed, put Melanie in her cot and went to phone him. We were on the phone at home. I just told him to come to the hospital as soon as possible. He wanted to know what was wrong, I couldn't tell him over the phone. He was saying, 'What's wrong, is there something wrong with baby, are you all right?' I just said come as soon as you can, then I got back on my bed waiting for him.

I felt as if the bottom of my world had fell out. I didn't know what to say to him, how to put it in words, after him being so thrilled. How do you say it?

Anyhow, I saw him at the top of the ward looking for me and I went to meet him. I don't know whether I walked or ran. I know the tears were streaming down my face and all the other women were looking at me. All I could see was his face, he looked white.

One of the nurses let us go in a little office at the top of the ward. When we got in he put his arms around me and said, 'What's wrong love, why are you so upset?' I'll remember my next words for the rest of my life and the look on his face when I said, 'Melanie, she's a mongol,' nothing else was said then for a few minutes I just broke down crying again. Then he said, 'Tell me all that was said', and I told him everything what the doctor had told me and the fact that he had to go to the hospital the next morning to see him.

(Cunningham and Sloper, 1977, pp. 341–3)

2.3 In the report from which this extract comes, Cliff Cunningham and Tricia Sloper described the events surrounding parents' discovery that their child had Down's Syndrome; they found that what parents usually wanted did not always happen. Of 30 families interviewed, 28 thought they should have been told in the first week, but only 20 were actually told in that time, and only 15 were told in the first two days. There is no difficulty for experienced paediatricians in diagnosing most Down's Syndrome babies. These delays are not because of any medical uncertainty; indeed, 19 of the parents suspected something was wrong before they were told. There is some evidence that the medical profession is increasingly realizing that parents want to know quickly. Janet Carr did a similar study in 1970 and found that less than two-thirds of parents in her sample were told within one month, whereas in Cunningham and Sloper's later study 25 out of 30 were told within a month. Nevertheless, unnecessary delay and prevarication continues.

2.4 But it is not only the timing of 'the telling' that parents often find unsatisfactory, but the manner in which it is done. You will recall the brutal comments that William's parents had to endure described in the case study you read in Unit 1/2, 'William: a child with Down's Syndrome'. Melanie's mother was made to suffer a tragic and private event in public and without the support of her husband. This is not uncommon. Cunningham and Sloper found that although 19 of their sample of 30 parents would have preferred to be told together, only nine were. Many complained that they had been told in the

presence of audiences of students, nurses or secretaries. Many also commented on the bluntness and insensitivity with which they were told. Sometimes this amounts to sheer brutality. We know of one consultant who said to the parents of one handicapped child, 'I see this as a disposal problem.' He argued that this approach got a reaction which gave him crucial information about parental attitudes in a way which more circumspect tactics would not. Bluntness is not limited to the cases of mentally handicapped children. Take this example of the confirmation of two three-year-olds' deafness:

> Yes he just said those three things, he just said 'She's deaf, backwards and got a deformed head. Next'—you know. It was horrible.
>
> He asked me first of all if I thought he was deaf and I said, you know, I had a slight thought that he might be. He just turned . . . we were both there and he just said 'Oh, your son's got to wear a hearing aid in one ear, we think he's deaf.' Rather lax I think in the way they did approach it. They didn't offer any help or advice like that, he just said 'Ricky's deaf.' Full stop.
>
> (Gregory, 1976, pp. 157–8)

It is difficult to know what else a doctor can do but put the facts before the parents, but what these parents and many others find hard to take is that they are given so few facts and no help or follow-up. Another mother of a deaf five year old was much happier: 'We took him and saw a specialist. And we were there a full hour and he gave him the works. He was marvellous, he really was, it was a thorough examination. And he explained in detail' (Gregory, 1976, p. 157).

2.5 Parents also feel hurt when doctors offer them a pessimistic outlook for their child. Mary McCormack tells of one mother who discovered her child was mentally handicapped when he was about 12 months old: 'One day, one of the doctors called me into his office. He said, without any preamble: "I suppose you know your child is mentally handicapped and will never go to a normal school." ' (McCormack, 1978, p. 27).

2.6 It is very apparent that many parents get less than full consideration from the medical profession, but perhaps it's more worrying in our supposedly enlightened times that parents' complaints do not seem to abate as the years pass, nor are their fears and worries often accorded the attention they merit. Cunningham and Sloper found that half of the mothers of Down's Syndrome children who suggested to the hospital staff that something was wrong were reassured that all was well.

2.7 In the case of disabilities like deafness which do not reveal themselves until some time after the birth, parents are one of the primary sources of information, especially since so much emphasis is placed on the early and rapid identification of hearing loss so that remedial action can be taken as soon as possible. Yet Susan Gregory found that many parents had to fight to get the medical authorities to take notice of them. The first of the mothers quoted below has a severely deaf son, and the second has a profoundly deaf daughter:

> I tried to tell them, I knew straight away there was something the matter with him and I thought it was his hearing when I saw him in the Prem [prematurity] Unit, but then we kept working on it and when he was about five months old took me continuously taking him to the doctors from when he was five months until he was nine or ten months, and to get the doctor to get me an appointment with a specialist. The doctor kept saying I was just a silly mother.
>
> At seven months she had a hearing test, and they told me both her ears were perfect, and I had to fight to get her another hearing test . . . I had the Health Visitor call, she'd be about seven and a half months, to ask me if she'd had all her injections and the hearing test and that, and I said yes but I wasn't quite satisfied with the hearing test so she arranged . . . well in actual fact she told me not to be silly, that they'd know their job you see, so I still said I wasn't satisfied, that I'd like another one; so of course they weren't quite sure the second time.
>
> (Gregory, 1976, pp. 150–52)

2.8 These mothers were not isolated cases, as you can see from Table 1, which shows the time between the parents' first approach to their doctor and the confirmation of deafness. You'll see that for one in four of the 122 children the process took over six months. Professional reluctance to take information from parents seriously is a common

A five-week-old thalidomide victim. Such a baby can shatter parent's hopes . . .

. . . but we all grow up. An eighteen-year-old thalidomide victim working in a clothing factory.

phenomenon, and not just at this stage. It is something that characterizes many parent-professional relationships throughout a handicapped child's career, as we shall see. Later in this unit, and in Unit 7, we shall be investigating the reasons for this.

Table 1 Time between approaching doctor and confirmation of deafness.

	Percentage of 122 children
0–2 months	30
3–4 months	17
5–6 months	12
7–12 months	16
13–24 months	7
Over 2 years	2
Mother didn't realize until told	12
Mother couldn't remember	3

Source: Gregory, 1976, p. 153.

Reading Now read 'From normal baby to handicapped child' by Tim Booth in the Reader (Reading 4.2). This article looks at the identification of severe mental handicap slightly later in life, when there is considerably less certainty about the child's status. It illustrates some of the conflicts that can arise between parent and professional.

Comment For the doctor, subnormality is a problem of signs, diagnosis and correct labelling, while for the family it is one of daily living. Booth argues that the diagnostic or clinical label may change the status of the child, from someone with grave problems to a member of a *class*—the subnormal—who are seen as possessing a collection of fixed attributes. Those who experience the handicapped child as a member of their family may have a very different, more natural, more human view of the child. Once given and accepted (and it is not always accepted), the clinical version of the child may shape parental perceptions so that they see their child as a member of this class. But Booth argues that parents are resistant to giving up their view of the child as 'normal but with a handicap' and not as a class member.

Some parents are resistant to accepting the professional view of their child and many dispense with the professional view, sustaining a deep conviction of the attachment of the child to the world of normality despite his handicap. One of the most valuable notions in this article is the one which challenges the view that parental opinions that their child is normal are self-deceptive or pathological. Other writers, such as Margaret Voysey (1975), have taken the view that parents of handicapped children usually accept professional definitions of their child. This can and does happen; but Booth shows that this by no means the inevitable outcome. If the diagnostic process is as social as he argues, it could be different. If we had no concept like 'subnormal' we might find it easier to push aside the clinical veil and begin to see such children as they are—as their parents do.

2.9 To conclude this brief consideration of the first, and perhaps heaviest, blow that parents of handicapped children receive, there are two general points to make. First of all, the identification of handicap is the first time professionals begin to impinge on parents. This makes family life, normally a private process, into a *public* series of events, and for many children it is the beginning of life that will involve many people outside the family who will exert an influence on them. For this reason, people sometimes speak of the 'career' of handicapped children—a lifetime in which, once they are 'on the tracks', many options are reduced and other special options, not normally accessible to others, are opened up. Secondly, the identification of a handicapped child is unusual among other public and unfortunate events in that there is no clearly established ritual for the parents to follow as there is when someone dies, or when a divorce takes place. It is often claimed that rituals can relieve stress and reduce uncertainty in such circumstances, but the birth of a handicapped child has to be dealt with individually by parents and doctors.

2.10 Severely handicapped children affect the lives of the members of their families far more than is commonly understood. Accounts of the lengths to which parents will go in order to care for their children and keep them at home provoke sheer admiration.

Reading Now read 'Caring for a mentally handicapped child: the daily routine' (Case study 16). As you read, make a list of the kinds of changes to family life that have resulted from these children.

Comment (a) The effects on the parents vary dramatically depending on the nature and abilities of their children. It is not safe to make general statements about the problems of families with severely handicapped children.

(b) Sheila's and Paul's mothers' lives are restricted. They have to be in almost constant attendance when the children are at home, and school time is spent catching up on housework.

(c) Parents' health may be affected, particularly by problems of night-care and the general strain of constant care and attention.

(d) Extra expenditure is incurred on items such as nappies, clothes and washing.

(e) Paul has put a strain on the personal and sexual relationship of his parents.

(f) School serves not only to educate these children but also to give their parents much needed relief from the burden of care.

Practical problems

2.11 In a survey of 303 families with severely handicapped children of many kinds in the North and Midlands, Sally Baldwin (1977) provided many examples of the practical difficulties that families have to overcome, most of which have considerable financial consequences. The problems are not simply those of day-to-day care: one third of the families she interviewed had been forced to move house because their existing house had no garden, was too small or had no downstairs toilet. A further third had had to make major adaptations to their house, such as the father of a twelve-year-old physically handicapped girl who had built an extra extension, installed central heating because his daughter suffered abnormally from cold, and put ramps down to allow her to get in and out of the house in her wheelchair. Half of these families had paid for the adaptations themselves.

2.12 Many severely handicapped children also inevitably increase the wear and tear on furniture and decorations. Sometimes this happens because the child is disturbed as in the cases of these two mentally handicapped children, one aged four, the second, fifteen:

> Her room's wrecked every morning, absolutely wrecked. I've just bought her a new bed at the weekend . . . We reckon by the end of this year we'll have to get her another new bed.
>
> Of course, if you count the things that he breaks. Quite a lot of crockery. Things like that and windows. He puts his fist through in temper like that, and when he's annoyed several times he's put his fist through the kitchen window. He put it through the bedroom window one day because it was raining and he wanted to go to (the seaside).
>
> (Baldwin, 1977, p. 10)

Other wear and tear arises directly from physical handicaps: wheelchairs and calipers, for example, can quickly wear out carpets, damage walls and destroy furnishings.

2.13 Incontinence constitutes an enormous difficulty for many families. Many physically handicapped children continue to be incontinent throughout childhood and on into adult life. During childhood their parents must provide for them. Severely mentally handicapped children frequently take much longer to toilet-train than normal children. Sally Baldwin estimated that in 1975 the additional average weekly cost for families with

An important adaptation for this boy with muscular dystrophy. To organize modifications like this, parents need time, effort and knowledge of available services.

incontinent children was £1.30, which covered the cost of nappies, rubber pants, extra washing and various accessories. But the extra time mothers must spend has to be added to this cost. With younger children, many mothers feel incontinence is less of a problem. Sheila Hewett (1970), in a study of children with cerebral palsy up to the age of eight, found 67 children out of 180 were doubly incontinent, but only eight mothers said this was their biggest problem. Mothers of older mentally handicapped children interviewed by David Wilkin (1979) found that life often revolved round changing and washing nappies, disposing of smells and finding toilets. Clearly the social unacceptability of incontinence in older children, particularly those who cannot care for themselves, imposes a major burden on parents.

2.14 Incontinence is one reason why many severely handicapped children need more clothes than most children. Another reason is the destructive behaviour of some children, such as this one:

> The way she gets through clothes and tights—it's tremendous . . . and shoes, every four weeks. I used to buy her Clarks shoes, but at £5.00 a time I can't afford to . . . She's got two anoraks, but she's broken the zips on both of them. She chews them and then pulls the zips off and that's it. And not only her clothes get destroyed, our clothes get destroyed too. She rips our clothes because she bites.
>
> (Baldwin, 1977, p. 25)

Other children wear out clothing because they have mobility problems or because of the heavy calipers they must wear, such as this fourteen year old with spina bifida: 'All her coats, the arms get worn out . . . She can get through a pair of tights a day because of her calipers, and her knickers don't last two minutes because she sits on top of her calipers and it all wears and tears' (Baldwin, 1977, p. 25).

2.15 Food and feeding presents difficulties for many families, some because their children require a special diet, others because the children have to be taught slowly and painstakingly to feed themselves, and others because they need adaptations to cutlery and crockery.

2.16 Transport is also a considerable concern, both because extra transport costs are often incurred getting children to and from hospitals and clinics and because it is often very difficult for parents to use public transport. Area health authorities are responsible for providing transport judged to be 'medically necessary', but Sally Baldwin found that, in practice, ambulance services were rationed so they excluded trips to out-patient

departments, speech therapy and physiotherapy. Apart from this the parents she interviewed found ambulances were often very unsuitable for their children and in some areas even refused to take wheelchairs. Thus, one mother with a child with spina bifida:

> I discovered when she was growing up a bit that ambulances weren't insured to take wheelchairs, so that was another problem . . . I'd bought her a little folding pushchair . . . So I said to the ambulance driver 'Take that for me' and he said 'What do you mean, you'll be wanting us to stop and do your shopping next.' I said 'Are you taking it?' and he said 'No' . . . So I stopped at home that day.
>
> (Baldwin, 1977, p. 14)

The ordinary transport and mobility required by any family in order to get about for household duties and recreation are also curtailed in some cases, although in other cases outings provide a much-needed break for parents and child. Nevertheless wheelchairs don't fit into buses, and disturbed or unusual behaviour causes embarrassment in public.

2.17 So there are many practical tasks that parents of severely handicapped children face that other parents never need to worry about, and there are others which parents of handicapped children have to continue to perform for a child long past the time when ordinary children can care for themselves. These tasks do not apply to all handicapped children; each disability presents its own problems and there is enormous variation in children's need for care within each group, but all parents at some time will face extra care tasks.

Teaching children to cope for themselves

2.18 It is not simply that children take longer to develop the skills to look after themselves, but also that parents have to think about actively teaching these skills to many children, and this presents an added burden and responsibility. In a later section we shall be discussing professional help with these tasks; here it is useful to illustrate the range of problems that parents face in teaching their children to look after themselves so that the children learn to be independent as soon as possible.

2.19 Sometimes parents will go to considerable lengths to teach their child, primarily in order to relieve the pressures on the family. Take, for example, this family:

> One family conceived a plan to get their twelve-year-old [mentally handicapped] daughter out of the habit of night accidents that involved mother, father and two older sisters. Waking her up once or twice a night did not work, so working in shifts, they got her up at half-hourly intervals and took her to the toilet. It took her three weeks to catch on,' her mother says, 'but that is fairly quick considering how long other things take her.'
>
> (McCormack, 1978, p.58)

Parents are often fairly sanguine about teaching their children to care for themselves. John and Eileen Wilks (1974) wrote a book about how they taught their Down's Syndrome son Bernard, in which they said: 'There was no pleasure in teaching Bernard to eat, but it had to be done. Like every other child, Bernard needed to be taught the techniques and social graces that make up the fabric of our lives' (Wilks and Wilks, 1974, p. 61). In Bernard's case, the social grace of using a knife and fork competently took 12 years to acquire.

2.20 Particular handicaps present particular problems. In the case of the severely deaf, Susan Gregory found that mothers had to devise ways of teaching children about dangerous situations because the children could not hear their mothers calling at them to be careful: 'By the time she was taking an interest in things like that, things that were dangerous, and could get them, she could lip read quite a bit. And I could tell her something was hot, and mime touching it and pulling my finger away—that sort of thing' (Gregory, 1976, p. 80).

2.21 Apart from the considerable expansion in home teaching and support services over the last ten years, there have also been a number of books written recently for parents offering advice on structured teaching of self-care and other skills. For example, Janet Carr's *Helping your Handicapped Child* (1980) and *Starting off* by Chris Kiernan, Rita Saunders and Chris Jordan (1978) offer detailed guidelines.

Social isolation

2.22 It is often claimed that parents, particularly mothers, of severely handicapped children are isolated as a result of their child. This may be because the demands for constant care and attention at home mean that mothers cannot get out, because alternative short-term care is not available, or because people are embarrassed or upset by the child and so avoid social contacts with the family. Yet how many parents do actually feel isolated is not clear. Certainly this mother of a six-year-old Down's Syndrome girl had had her social life considerably curtailed until her son was old enough to baby-sit:

> It's only recently that we've been able to get out in an evening, but it has made such a difference to me. A friend used to baby-sit occasionally for Jane but I never felt happy about leaving her. I was always worried that something might happen. It is different leaving her with Michael. He knows her as well as we do and I can rely on him to see that she's all right.
>
> (Wilkin, 1979, p. 137)

2.23 In his sample of 60 mothers of severely mentally handicapped children, David Wilkin found that only 70 per cent went out to work, most of them part-time, 40 per cent couldn't get out in the evenings and 90 per cent had no free time at the weekends. Just over half of the mothers wanted to get out more, and over 60 per cent wanted to work, or to work full-time if they were already working part-time. Certainly many of these mothers wanted more freedom and time to themselves, but it isn't clear that this is any different from the mothers of normal children who may (and often do) feel hemmed in by their caretaking functions.

2.24 In her study of 180 mothers of cerebral palsied children, Sheila Hewett found that a minority, 21 per cent, felt lonely, but their feelings of isolation were not related to the amount of contact they actually had with friends and relatives. There were some mothers who felt lonely and had a lot of contact with other people, and some who didn't feel lonely who had very little contact. Feeling isolated had more to do with the particular kinds of contacts mothers wanted, the options open to them and their personal response to the situation. So, for example, one mother with ten children, all under 11, one of whom had cerebral palsy, said: 'Well, I admit I've got one or two children, but there's times when I think to myself I should like to go out, even if it's only down to a friend's—or anywhere. I've always said you can be lonely even if you've got a houseful of children' (Hewett, 1970, p. 117).

2.25 Again, this is a reaction one might expect from *any* mother. It is worth emphasizing this point, because it's very easy indeed to think that parents of handicapped children are expressing views which stem from their particular situation, when in fact everyone thinks like that in similar circumstances, whether or not their child is handicapped. It is always important then to compare families of handicapped and normal children to discover what the real effects of handicap are. Thus, the mother of a cerebral palsied child said about baby-sitting: 'No, my husband won't leave her, only with my mother. He feels she's the only one capable.' How easy it might be to classify this as 'over-protective', unless you know that many mothers of normal one year olds gave similar replies: 'Oh no, we never go out—my husband would never go out—he wouldn't let anyone come in and let us both go out.'

2.26 Problems which limit children's mobility can also limit the parents' social contacts. Some of these problems have their source in the children, others in people's reactions to them. Mentally handicapped children who are behaviourally disturbed can cause particular limitations: 'He's fifteen and a handful just now, getting very vicious. He is on special pills to calm him down but they don't seem to be working. He shouts all the time on the bus, so none of the family like taking him out very much' (Baldwin, 1977, p. 12).

2.27 On the other hand, mothers are fully aware that people's reactions can be unreasonable because of ignorance, and they often become more determined to soldier on: 'The times I've heard people say, loud enough for me to hear, "If he was mine, I'd teach him manners." You don't know whether to give a speech to this gaping crowd, to ignore it or hit the old bag. Or maybe I could pin a notice on him' (McCormack, 1978, p. 69).

2.28 The mothers of deaf children interviewed by Susan Gregory also came up against these problems. Many of the children tended at times to be anti-social, or occasionally

uttered strange noises which could embarrass people. Responses of mothers varied a lot, from, 'To some extent it ties me . . . because he's not been a really well-behaved child, I will not take him to say, a coffee morning', to, 'Anywhere I go, he goes'. Susan Gregory was also able to compare how often the mothers of four-year-old deaf children went out with a sample of mothers of normal children, and she found the replies were very similar, so these deaf children did not appear to restrict their mothers in that way.

2.29 So it is true that some parents, particularly mothers, of handicapped children are isolated, but for many this is not to do with their child. Where they are isolated, however, it may well be that the burdens of caring for their child are felt even more, and, as we shall see, one of most strongly expressed needs of mothers of severely handicapped children is for some relief from that burden.

Do handicapped children produce abnormal families?

2.30 There is no doubt that families with a severely handicapped child shoulder a considerable burden in caring for their child, but what are the consequences of this for the health and emotional well-being of the family members? Are marriages put under stress and broken? Do brothers and sisters become unusually jealous of the attentions given to their handicapped sibling? Do parents become physically ill or emotionally disturbed?

2.31 Before looking at these questions we should first of all look at how the burden of caring is distributed about the family. Is it the case that extra child-care tasks fall onto mothers who are still the principal caretakers in our culture, or do fathers step in more to help? The evidence suggests that the same patterns obtain as they do in other households. Susan Gregory compared the extent of fathers' participation in the care of her sample of deaf children with Sheila Hewett's sample of cerebral palsied children, and with a sample of normal four year olds. Mothers were asked how often fathers bathed or dressed children, read to them, told them stories or sang to them, took them out or looked after them without the mother. Fathers were then rated as highly or fairly participant, or non-participant. Table 2 shows the results.

Table 2 Fathers' participation in caring for handicapped and normal children.

	Highly participatory Percentage	Fairly participatory Percentage	Non-participatory Percentage
Deaf 4 year olds	65	33	3
Cerebral palsied children under 7 years	50	38	12
Normal 4 year olds	51	40	9

Source: Gregory, 1976, p. 174.

2.32 You can see from the table that there is a slight tendency for fathers of deaf children to take on more tasks than other fathers, but the similarity between the groups is striking. Nevertheless, this scarcely shows that the burden of care is shared, for the mothers were not asked about housework, washing clothes, toileting and feeding. In these tasks as well, there is evidence that the normal pattern occurs: mothers perform these duties. David Wilkin, in his study of severely mentally handicapped children's families, found that only 24 per cent of fathers shared the work of feeding, 20 per cent shared toileting and three per cent shared clothes washing. But, in agreement with the findings in Table 2, 53 per cent baby-sat in the evenings and 49 per cent at weekends. It seems, then, that where a handicapped child imposes an added burden that is within what fathers are normally expected to do, the father will step in, but where the extra burden is within a traditionally female area, such as toileting, he is much less likely to, and so the bulk of extra child care falls on the mother. But there is *always* variation, as you can see from these two mothers of severely mentally handicapped children:

> She depends on me you know. Well I think a woman should do these jobs, but when he was off he wouldn't even change her nappy, even if it was only wet he wouldn't change her. He said: 'You see to her, I'm not doing that.' Linda hasn't made any difference to him. He's always gone out. I'm the one who's had her, he hasn't done anything.

> I feel that parents should combine and each do whatever happens to need doing. For instance, changing nappies and feeding children, that's a women's job technically, but John helps me with that. We share the jobs. He'll cook a meal if necessary and he always washes the dishes.
>
> (Wilkin, 1979, p. 124)

2.33 The added burden on mothers does cause them to feel much more stress. Jonathon Bradshaw and Dorothy Lawton (1978) investigated this in a sample of over 300 mothers of children with a wide range of severe physical and mental handicaps. They gave mothers the 'malaise inventory', which is a series of 24 questions designed to identify how stressed they felt, such as, 'Do you often feel miserable and depressed?' and, 'Do you often get into a violent rage?' They found that, on average, mothers replied, 'Yes' to just over nine of these questions. This is considerably higher than the scores of three and four found in large samples of mothers with normal children (Rutter *et al.*, 1975). Not surprisingly, David Wilkin found in his study that fathers felt much less stress: only 18 per cent complained of 'mental health problems', compared with 72 per cent of the mothers.

2.34 But these predictable results do not necessarily lead to a higher number of breakdowns or visits to GPs for help. Ann Gath (1978) compared a group of parents of Down's Syndrome babies during the first two years after birth with a comparable group of parents of normal babies. She found that the Down's Syndrome parents were no more likely to seek the help of their GP, nor was there a higher incidence of psychiatric illness. She did find many mothers were depressed, but 'the depression was regarded by these women as being an understandable "normal" reaction to the circumstances and, as they did not believe a doctor could remedy the basic cause, they saw no reason to consult one'. The mothers in her sample who were severely depressed attributed their upset not to the problems of coping with the child, but to the grief they felt about what had happened to them, and their anxiety about the future for them and their child. In fact, twice as many mothers of Down's Syndrome children experienced serious depression in the 18 months following birth than did mothers of normal children.

2.35 There is a lot of conflicting evidence about the effects of severely handicapped children on marriages. It has been suggested that the presence of a handicapped child *intensifies* patterns of relationships which preceded the birth of the child, so that the loving, supportive marital partnership will emerge stronger and more enduring as a result of shared stress, while those relationships which were less secure flounder under the practical, financial and emotional difficulties. Compare these two mothers of deaf children: 'It's imprisoned us. It's made us do a lot more quarrelling, not that we didn't quarrel before but it's increased horribly.' 'I don't know whether it's Samantha, but I think we're more in love now than we ever were—it's not driven us apart, I give it that' (Gregory, 1976, pp. 178, 180).

2.36 Ann Gath found that parents of Down's Syndrome children were more likely to have an antagonistic relationship than other parents, and some of this had to do with the disruption of their sexual relationship that several couples had suffered after their baby's birth. Over a longer period, Tew, Payne and Laurence (1974) found that, among parents of children with spina bifida, the divorce rate was twice the national average. Thus it appears that a handicapped child can add a stress to a marriage which in some cases can result in the breakdown of the relationship. Certainly a handicapped child provides opportunities for conflict, particularly surrounding traditional sex-roles, as these two parents (not married to each other) show:

> He sits there, doing nothing, watching me coping with the normal child and the handicapped one . . . I sometimes hear him tell people how well I manage and I feel like screaming. I have to manage. Half the time he is out, the rest of it he is just sitting watching television. He doesn't want to talk about it. It's my problem.
>
> I think my wife thinks she is the only one to suffer, but I have to lead two lives. She gets the sympathy, I don't. I don't tell people at work because people go funny and watch what they say to you if they know . . . Then I have to come home and face all the upset here, as somebody different. I'll admit I stop for a few drinks before I come home most nights. I need it.
>
> (McCormack, 1978, pp. 129–30)

2.37 Finally, while considering how families are affected, we should look briefly at the brothers and sisters of handicapped children. In a survey of families with a child with spina bifida, Margaret Woodburn (1975) found parents expressing the opinion that the other (non-handicapped) children in the family were affected by the presence of the disabled child. Two-thirds of mothers said they spent more time with the handicapped child and many were sure that this was noticed and resented by their other children. Some of the brothers and sisters voiced complaints, such as, 'You spent a longer time kissing him good night than you did me,' others acted out their feelings by demanding more attention or showing signs of precocious independence. By contrast, Philp (1978), in a study of families with a physically handicapped child, could find no evidence that normal siblings received less attention. Susan Gregory, in her study of deaf children, found that there was a slight tendency for sibling jealousy to be greater than in normal families, but, as we might expect, there was a great deal of variation between families. It has been suggested that the arrival of a severely handicapped baby puts a strain on brothers and sisters and so they are more vulnerable to emotional and behavioural disturbance. Ann Gath investigated this with the brothers and sisters of Down's Syndrome children, but could find no evidence of higher rates of disturbance than in normal families, either in their parents or their teachers' feelings about them.

2.38 If these results appear confusing, that is entirely to be expected. After all, why should anyone expect siblings of handicapped children to all react the same way? No one expects this with normal children: some brothers and sisters get on, others don't.

Brothers go up in their personal lift at home.

Reactions can be as diverse as these: 'We recently met a family with a 12-year-old Down's, and our nine year old asked, "Will Jeff look like that when he's grown up?" I said he might and she said, "Then don't tell anyone he's my brother" ' (Darling, 1979, p. 164). 'I don't believe Peter will live a long life . . . It is unlikely he will outlive our parents, but if it does happen, Krystyna (his sister) and I will look after him. He would live with one of us as part of our family. Any girl I marry will have to accept that' (McCormack, 1978, pp. 157–8).

2.39 Much has been written in the past about the feelings of guilt, over-protectiveness and resentment which handicapped children evoke in their parents, asserting that parents don't learn to 'accept' their child, that they cover this up by spoiling him or her, and so on. There are as many vague assertions as there are professionals prepared to make them. Not so long ago, doctors were convinced that mental and physical exhaustion would result from the birth of a handicapped child. Aldrich, in 1947, in a highly respectable journal, advised parents to place severely handicapped children in institutions as soon as possible. Ann Gath, herself a psychiatrist, tells of hospitals where mothers were not even allowed to see severely handicapped babies, who were summarily removed to long-stay hospitals. Another psychiatrist, A. I. Roith, writing in the early 1960s, had come to expect from the literature 'a horde of guilty and aggressive parents' (Roith, 1963). They never materialized. Although automatic institutionalization does not happen now, it is very easy indeed for professionals to graft their own theories about families onto the evidence in front of them, even if the match is not good. Why and how this happens we shall examine in the final section of this unit.

2.40 The majority of parents want their severely handicapped children to be at home with them, and go to great lengths to make this possible. Very few reject the child outright. Margaret Woodburn (1975), in her survey of ninety-five spina bifida cases, found that only five were institutionalized and four of these were illegitimate children. However, pressure for placing the most severely handicapped children in institutions does build up as children grow older. David Wilkin found that the majority of children on waiting lists for long-stay hospitals were aged eight to 13, and also tended to have more problems with physical health, were more likely to be totally incapable of moving about, feeding themselves, washing or dressing, and tended to have more behaviour problems. These differences are only tendencies: there were many totally incapacitated children who were not on hospital waiting lists. The following account explains one set of circumstances that surrounded admission to a hospital:

> Linda E. is now twenty-one. She has been a permanent resident in a long-stay hospital about twenty miles from her home since she was seventeen. June, her mother, is an infants teacher. Her father, Jack, is a telephonist. They have three other daughters, Liz (twenty-three) who is now married and away from home, Gillian (sixteen) and Helen (thirteen).
>
> It was mainly for the sake of the other girls, June says, that they decided on residential care for Linda after years of refusing to consider the possibility.
>
> 'The girls were growing up, bringing home friends. They are entitled to a life of their own. You have to decide whether to sacrifice the whole family for one and it is a decision only parents themselves can make. I wouldn't presume to give anyone else advice.'
>
> Another reason: 'I'd always managed when she was younger but I started feeling I couldn't keep it up. You grow out of having babies and toddlers around. You get too old for it. That's what Linda was, a permanent toddler. Maybe I just got past it.'
>
> Linda's behaviour, always difficult, had become increasingly bizarre as she grew up. Even the little idiosyncrasies that did not change were much more embarrassing in a normal-looking young woman than in a child.
>
> *June:* 'She would hit people in the chest as you walked along the street. It was her way of communicating but people don't know that. I'd come home with my heart in my boots because she'd behaved badly and someone had made a nasty remark.
>
> 'At home chairs were wet and soiled, windows smashed and food thrown about. She could wreck a room in five minutes flat. She wrecked Helen's dolls and once she got out the floor polish and spread it all over Gillian's school exercise books. Gillian is the sort who takes everything in her stride. Liz being older, was like a second mother, but I think Helen suffered. She got the worst deal.

20

'When she was little, I always seemed to be sticking a dish of food in front of her in a high-chair and rushing off to do something else. There was never time for her.

'I suppose the worst thing that happened with Linda was when she started menstruating. She would be sitting quietly anywhere, then suddenly she would fish around and bring out a pad, which she would toss over her shoulder. Like producing a bunny out of a hat. If you thought too much about the embarrassment her behaviour caused, you'd have gone out and shot yourself.

'I took her to the Children's Hospital for her usual check-up—she was on drugs for convulsions—when she was getting on for sixteen and due to leave Special School. The doctor always used to ask me how I was coping and this time I said I wasn't coping very well, which surprised him. He thought we should try sending her away, for a trial period. My instincts were against it, always have been. Linda was part of the family, but as the doctor put it, she was not the whole family.

'Jack was dead against her going away, but then he didn't have all the work. He agreed to her going for a month to give me a break. There wasn't a permanent place for her even if we wanted it'.

(McCormack, pp. 176–8)

2.41 There is no question of these parents 'emotionally rejecting' their daughter. They did not particularly like the idea of her going away, they continue to be fond of her, but the practical and social difficulties were beginning to weigh heavy. And to this must be added the doctor's quiet encouragement of residential placement. This example illustrates a key dilemma for families with a handicapped child and the people concerned with them, for in the search to offer the *child* as normal a life as possible—something that has become a goal at least asserted by most policy-makers and professionals—it may happen that the *parents'* access to a normal life for themselves is limited. How far social, medical and educational services can help to avoid this dilemma will be a subject for the next section. Clearly, if services can be devised to enable children to remain with their families, and for these families to lead a reasonably normal life without stress, then that would be a major achievement.

Activity 1 We are going on to examine some of the services that are available to families with a severely handicapped child. Before you read this, consider the services that families would require.

(a) Summarize the main problems that families face.

(b) What is the source of these problems?

(c) What services alleviate these problems?

(d) If you were designing services for families, what policy objectives would you choose?

Services for families

Reading Now read 'Help yourselves: support services for parents of a severely handicapped boy' (Case study 17). This illustrates again, for one family, the problems of coping, but it also describes the difficulties they had obtaining help.

Comment (a) As much as any family, the Bowmans suffer from inadequate services such as housing, although their particular circumstances allowed them to do something about it.

(b) There is a long list of things they want help with. Some of these they could have obtained as a right when this account was written in 1972, such as incontinence aids.

(c) They have had to struggle to obtain services from their local authority, and have not found social workers practically helpful.

(d) They particularly feel the need for short-term care to relieve the burden of looking after Tom.

Practical and financial help

2.42 In June 1971 the government produced a White Paper called *Better Services for the Mentally Handicapped* (DHSS, 1971), in which it was written: 'Each handicapped person should live with his own family as long as this does not impose an undue strain on them or him, and he and his family should receive full advice and support.' Something strange was going on, because at the same time the government forecast a 15 per cent rise in residential places, and the White Paper contained no actual figures for the amount of services to families that were anticipated. But what *do* central government and local authorities do to help families with handicapped children, and was the implicit theory in that White Paper, that services could help keep children out of institutions, correct?

2.43 It has to be said that governments over the past 20 years, whether Labour or Conservative, have not distinguished themselves by their efforts to help meet the needs of handicapped children and their families. There are three principal financial benefits we are going to discuss below: the attendance allowance, the mobility allowance, and the family fund. The first of these was introduced by the Labour government in 1970 but implemented by the Conservatives in 1971. The second was first proposed in a White Paper in 1974 (DHSS, 1974), but was not introduced until 1976. Although any help is worthwhile, voluntary organizations were, according to one of them, 'united in fury' at at what they saw as the government's failure to pay an allowance as a right to all disabled people. The family fund emerged in 1972 as a direct result of the public furore over thalidomide children. Sir Keith Joseph, then the Secretary of State for Social Services, was under considerable pressure to set up a trust fund as had been done in other European countries. Since he felt unable to discriminate against many other families with equally disabled children, he established a fund intended to help all families with a severely handicapped child.

2.44 The other principal legislation through which families may be helped is the Chronically Sick and Disabled Persons Act (1970). This act, which gave wide powers to local authorities, was a private member's bill and was rushed through by the Labour government just before the 1970 election. Government planning, then, lead to the attendance and mobility allowances; other forces were at work for the other measures.

2.45 The attendance allowance—you will recall that the Bowman family received this—is intended to help handicapped people, both adults and children, who need a lot of personal attention. It is awarded to around 40,000 severely disabled children at the moment—only half of the total, according to recent estimates (Bradshaw, 1980). To establish eligibility, a doctor visits the home and assesses the degree of attention and care required, and after this the attendance allowance board takes a decision on whether to award, but the allowance is given irrespective of the family's existing financial means. Not surprisingly, administrators have been put in the invidious position of taking decisions in marginal cases: one particular refusal—the case of Jimmy Martin in 1972—provoked a public and press furore, but the government was quite resolved that the attendance allowance should be seen as just that, and not as a general disability benefit, as they stressed in their 1974 White Paper. David Wilkin's survey of families of severely mentally handicapped children showed that, although this allowance was welcome, it was not without problems:

> There were many who had learned of their right to claim only through talking to other parents, some of whom had endured a long struggle to obtain the allowance. In families where the handicapped child was able to go for regular periods of short-term care, family finances were disrupted because payment of the allowances was stopped whilst the child was away from home.
>
> (Wilkin, 1979, p. 104)

2.46 The mobility allowance was introduced to replace the invalid trike and was originally intended only for physically disabled adults. However, the government decided to extend it to children over the age of five who were unable to walk. It is a relatively generous benefit (£14.80 per week in 1980–81), although it is taxed. The restriction of this benefit to children who cannot walk has been criticised by Jonathon Bradshaw (1980), who argues that there are many other children who can walk but who have serious mobility problems all the same. This is most obviously true of mentally handicapped children with disturbed behaviour who cannot be taken on public transport. He

argues that if the benefit was intended to increase the mobility of children outside their home and to compensate parents for their added financial burdens, then the criteria for eligibility are illogical. Kenneth Cooke (1980) has argued that these problems arose because the mobility allowance was not part of a coherent government strategy aimed at meeting handicapped children's and their families' needs—it was 'tacked on' rather than planned.

2.47 The family fund is quite unlike any other social security benefit in the way it is administered and the way it was established. As we said earlier, it was established following the outcry over the attitude of the Distillers Company to thalidomide damaged children. The government gave an initial grant of £3 million to be administered by a private charitable trust, the Joseph Rowntree Memorial Trust, followed by a further £3 million in 1974. The fund was intended to help the families of 'very severely disabled children' under 16 who were living at home. Like the mobility and attendance allowances, grants from the fund are paid irrespective of how well off a family is, but unlike the other allowances, the amount of the grant is entirely up to the administrators of the fund, and it is given as one capital payment. Up to September 1977 the average grant was £348, but some families received as much as £2,000 (Bradshaw, 1980). Help to parents has concentrated on providing or contributing to the cost of cars and their upkeep, providing clothing and providing washing machines and other washing facilities, but families may apply for anything they think will relieve the burden of care—a number of families have been granted colour televisions where parents have argued that they are an important means of keeping their child quiet and interested.

2.48 The operation of the family fund illustrates some of the problems that can arise in such a discretionary scheme. Families who apply for grants are visited by a social worker who assesses their needs and makes a report. A lot can depend on which social worker visits the family: in the early days the social workers employed by the fund took the view that it was not enough to supply only what families asked for; they felt bound to discover what else they might need but had not asked for. This policy lead to a rapid run-down of the fund, which came dangerously close to disappearing. It also meant that wide variations in grants given to families with similar problems began to appear. The result was that the administration of the fund became more bureaucratic and rigid, and families were only given what they asked for. Even so, Jonathon Bradshaw shows that in some respects the distribution of the money has been unfair. Middle-class families have received a higher average grant than working-class families because, Bradshaw argues, the former have higher expectations and so ask for more. There are also regional differences, and, paradoxically, in the poorest region, Northern Ireland, families received the smallest average grant.

2.49 However, given the fund's finances, there is little that can be done about this situation. Something like one third of the families eligible for a grant have actually applied, but Bradshaw argued that if advertising increased the demand, the fund would not have the resources to cope.

2.50 Together, these financial benefits cost central government many millions of pounds each year, but what is their effect? Does money really compensate families of severely handicapped children for their extra troubles and pains? Does it help relieve the stress they endure? Jonathon Bradshaw and Dorothy Lawton (1978) have shown that a grant from the family fund, although it manifestly relieved the financial burdens of families, did not reduce the level of stress experienced by mothers. We mentioned earlier their use of the 'malaise inventory' with which they showed that mothers of severely handicapped children were on average more stressed than mothers of ordinary children. They also showed, very surprisingly, that, within the group of mothers with handicapped children, neither the degree of the child's handicap nor the family's financial resources were related to the mother's level of stress. Mothers in good housing, in a well-off family, were just as likely to feel stressed as mothers in poor housing on limited incomes. This is a very unexpected result, and one that was found right across the range of income. There were some families well below supplementary benefit levels in housing with no bathroom and no inside lavatory whose stress level was just as high as many more well-off families. Clearly, low income and poor housing are sources of stress, but their amelioration does not remove the child's handicap. Supplying extra money does not reduce the stress of having a handicapped child because money doesn't determine it in the first place. Bradshaw and Lawton conclude:

It appears that the relief of emotional stress may not be a feasible aim of public policy. Public policy may direct itself with some effect to the relief of the physical burdens, the monotony of care, the seclusion, the expense and so forth of caring for a handicapped child but, if the malaise score is a measure of mental well being or emotional disturbance, then it appears that it may not be relieved by the provision of goods.

(Bradshaw and Lawton, 1978, p. 189)

Short-term care

2.51 David Wilkin asked mothers of severely mentally handicapped children what they wanted help with but were not receiving. Here are the first four priorities:

1 Provision of some form of day care during the school holidays.
2 Longer school hours or alternative provisions after school.
3 Day care or play facilities for some time at weekends.
4 Some form of baby-sitting service or the development of voluntary baby-sitting groups.

(Wilkin, 1979, p. 186)

2.52 Mothers unquestionably want someone to share the burden of care with them. They want someone they can trust to look after their children for short periods and give them a break. Incidentally, for many of these mothers, school came as the first real relief. A number of schemes have now grown up around the country which offer short-term care ranging from evening baby-sitting to two- or three-week stays. In Leeds, for example, the 'Time Out' scheme provides temporary fostering arrangements for mentally handicapped children (Freeman, Crosby and Naylor, 1977). Voluntary foster parents are

The National Deaf Children's Society organize a volunteer service of 'dogsbodies' who provide short-term relief to parents of deaf children.

trained at a further education centre and are paid by the local social services department and the area health authority. In 1979, 25 substitute families looked after 78 children for periods of up to two weeks. There are similar fostering schemes, mainly for mentally and physically handicapped children, in many parts of the country. Others are based in institutions. The best known of these is probably Honeylands in Exeter, which has developed an integrated health, social service and educational support service (Goddard and Rubissow, 1977). As part of its service, Honeylands offers short-term care and baby-sitting. It is open all the time and is used by parents of mentally and physically handicapped children and by those described as 'socially deprived'. Some parents have a regular booking, others use the service to cope with crises. An important result of Honeylands' short-term care has been a marked reduction in the number of children going into full-time residential care in subnormality hospitals.

2.53 Just how important short-term care is for parents was emphasized by one mother, who learnt that her profoundly handicapped daughter could no longer be taken in by the local subnormality hospital in Cambridgeshire because of financial cutbacks:

> I got to the stage at one time when I thought to myself: 'We are getting closer and closer to a nervous breakdown, and if we don't get any back-up at all then we've got nothing to fall on'. . . I can look after her, I can manage her at the moment if I get that back-up. I mean we love her, we want her at home with us. She's one of the family.
>
> (BBC1 *Look East* report, March 1980)

This mother's plight was partly caused by the allocation of £1 million to Papworth Hospital, where a number of heart transplants took place in the late 1970s; its expensive services were draining the area health authority's funds. Not for the first time have the priorities of medical expenditure seemed inequitable.

Advisory and teaching services

2.54 A great many parents are offered advice by professionals on how to care for and educate their children. Sometimes this comes as part of the normal pattern of health care, such as visits from health visitors, but a number of schemes now exist which are specifically designed for parents of handicapped children. These schemes generally involve a professional visiting the home and working with the child and parents to encourage parents to teach their child. One group of children—the deaf—have had such a service in most areas for some time.

2.56 A number of home advisory services use a scheme initially developed in the US, known as the Portage project. This is typical of many schemes; the home visitor assesses the child at home and select tasks he or she thinks are appropriate for the child. Visits then take place each week, during which the parents are taught how to teach a specific skill. An activity chart which sets out the tasks for the week is then left with the parents who spend anything up to an hour each day teaching their child. The Portage scheme has been used in South Glamorgan (Clements *et al.*, 1980) where children are referred by GPs and paediatricians. They are then screened and if they are significantly retarded they join the service, at an average age of 21 months. The Portage scheme is described in more detail in the case study on Westhall School in Unit 16 (Case study 45).

2.57 Such schemes serve a number of functions. First of all, they offer practical guidance to parents, and there is evidence that parents of less severely handicapped children in South Glamorgan welcomed the service. Wishart, Bidder and Gray (1980) found that families that had received the service whose children had IQs greater than 65 tended to put the home advisory service higher in their preferences for services than day care. Among these parents were a number who had seen significant gains in their child's development. However, parents of more severely handicapped children, who often had the experience of working hard with their child to little effect, put day care above the advisory service in their preferences.

2.58 Second, advisory teaching schemes put families in early regular contact with the professionals who will be part of their lives in the years ahead. This can cause as many problems as it can create opportunities. For example, there is some evidence from the evaluation of a home teaching service in Hull that regular visits by an advisory teacher may actually decrease the parents' independent skills. Sarah Sandow and Alan Clarke

A disabled girl plays with toys from a toy library. Toy libraries are often very valuable services usually run by parents with professional advice.

(1978) found that, in the long term, children whose parents were visited every two months developed faster than those visited every two weeks because, they argued, parents in the latter group came to depend too much on the advisory teachers. Clearly, this need not happen, but one can envisage how easily professionals might cease to support parents and come to supplant them in certain roles. Early professional involvement can be a further opportunity for domination and ignoring parents' knowledge of their own child, as this mother of a deaf child found:

> I used to have a peripatetic teacher, and I used to say—she can do this, and she can do the other, and he didn't believe me, and that's all there is to it. So I thought I'll prove she can do it, when there's nobody at home I taped her, and she was very clear on it.
>
> (Gregory, 1976, p. 130)

Early intervention can also be an early opportunity to induct families into that career of which we spoke earlier, with options restricted and decisions made by the professionals according to their customary actions and categories. Another mother of a deaf child said of the child's teacher, 'He's not the sort to give you any hope, not really. I mean at first, the first words he said to me when he came round to see me about Heather were "Your daughter will have to go away when she's six" ' (Gregory, 1976, p. 131).

2.59 A residential school may well have been the only option in this case, but how easy it would be in other cases for children who become known to the professionals to find themselves channelled towards special schooling, while others who escape the net might get to an ordinary school. This is highly speculative, and the evidence for it is at best circumstantial, but with many home teaching schemes extending to children who are only mildly delayed, the possibility remains. Thus early professional intervention can help or hinder. Schemes can be sensitively designed to meet parents' needs and advisers can be helpful and supportive, or schemes can be bludgeoning and advisers domineering. We heard recently of one early intervention scheme in an outer London borough which began with parent and child confronted in a child development clinic by a panel of 13 professionals. Any help they could offer must have been lost in the sheer terror of the experience.

2.60 A third function of early intervention schemes, particularly for children from poor homes, is to prevent later handicap. Unit 14 will be analysing how far they succeed in this.

Parents' needs and professional services

2.61 Now that we have looked at some of the problems parents face and some of the services available, let's conclude by examining how they match up, and whether we have made any progress recently in helping families. I suggest you look back to your response to Activity 1 before moving on. How far did your list coincide with the services we described?

Reading Now read 'There'll never be a time when I'm young and free' (Case study 13). Here, Mrs Whyatt says she has not been particularly helped by 'the system'. Make a list of areas where she could have been given more and better help.

Comment My list is:

(a) prompt diagnosis;

(b) better follow-up services after the birth;

(c) more practical advice;

(d) more detailed and accurate information about Down's Syndrome;

(e) birth control advice;

(f) prompt contact with families who have had experience of bringing up a child with similar developmental patterns;

(g) some leaflets which could be studied at home.

2.62 It is possible to point to many instances where professional services have helped parents, where they have felt reassured by doctors and cared for by social workers. Nevertheless, there comes a point where the weight of evidence of unhappy contacts between parents and services leads you to attribute the problems to something other than the personal failings of particular professionals. At the end of the unit we will be looking in more detail at these issues. For the moment, you might think about the following points. First, our society in general is bad at helping chronic problems, better at helping acute cases. We spend millions on prestige clinical hospitals backed by a powerful medical establishment whose future lies in high-powered research. At the same time we are

Parents and professionals together: a physiotherapist demonstrates activities with a boy with cerebral palsy.

relatively penny-pinching when it comes to helping the old, the chronically sick and the handicapped. Second, professional insensitivity is not just to do with personalities. It has also to do with status differences and with how large a part handicap plays in the lives of parents and professionals. Professionals are supposed to be experts and authorities and may therefore speak in authoritative tones and use unfamiliar language. To them, a handicapped child will represent only a few minutes of their time, to the parents, a life-time. Third, professionals are not representatives of their clients in the way solicitors are. They are paid by local or central government to act as agents of those authorities, and this can easily create conflicts of interest. They must act as controllers of options and resources, as well as suppliers.

2.63 Financial and other services for families have undoubtedly improved over the last twenty years. A study by Tizard and Grad in 1961 found that none of the families of mentally handicapped children they surveyed were relieved by short-term care, and that 83 per cent of the children had no pre-school day-care. These figures would not be obtained today. On the other hand, Tizard and Grad found that many parents complained of lack of understanding and support from doctors and social workers. This has not changed.

Self help

2.64 The response of some parents has been to fall back on their own resources, and develop self-help schemes in which groups get together to discuss their problems, share solutions and form more politically active pressure groups. One such group is 'Contact-a-family'. Set up in 1974, this scheme began with two full-time community workers in the London boroughs of Wandsworth and Ealing, who set up neighbourhood groups for mentally and physically handicapped children and their families. Through health and social services registers, families were identified and brought together regularly in groups of 30–40 families. The scheme defined its aims as:

> To give families with a handicapped child living at home contact with other families who are in the same situation and area as themselves.
>
> To bring together these families so that they can exchange information and share experiences; give each other mutual support, understanding and practical help.
>
> To enable these families to meet as near as possible to their home; to have frequent contact and somewhere central to meet and share activities.
>
> To give parents, through being part of a local group, the opportunity to press for better services and say collectively what their group needs are.
>
> To encourage families to organise services that they need locally, e.g. holiday play-schemes, baby-sitting and transport schemes etc.
>
> To enable families with handicapped children to benefit as a whole, not just the handicapped child but also the parents and brothers and sisters.
>
> To give these handicapped children and their families the opportunity to take a more active part in their local community.
>
> (quoted in Loney, 1981)

Contact-a-family now has a number of groups in London and an offshoot in Wiltshire, but further expansion has been stemmed by local authority cuts. Parents in Lambeth and Lewisham have campaigned for a worker to help organize a group without success. The scheme contains many activities: Saturday family clubs, evening parents' meetings, holiday playschemes, family holidays, an information service on local facilities, and meetings with professionals. Another service the groups offer is home visiting for parents who have recently had a handicapped child. Another parent is carefully matched to the family concerned, and over a series of visits this parent shares experiences and feelings and offers advice on services.

2.65 Another group, 'Kith and Kids', was entirely established by parents, and continues to be managed by them. This group, based in North London, was first established by the parents of a mentally handicapped girl. It began with fortnightly meetings on Sundays at which handicapped children and their families got together for various social activities. These days are carefully planned to provide everyone taking part with a range of appropriate experiences. In 1972, the group began work on what are now intensive regular education and training fortnights that occur each year in which psychologists are employed

to organize a programme of specific teaching. The teaching is done by volunteers who are assigned two to each child, hence the name of these schemes: 'Two-to-one'. Two-to-ones have been highly successful in many ways—children have learnt new skills and parents have gained new teaching skills. They have been limited only by shortage of funds and a difficulty in finding good psychologists. Kith and Kids possibly goes further than most self-help parents' groups in that it has set up its own teaching schemes, and it employs professionals (Collins and Collins, 1976).

2.66 In times of financial cuts, self help may undermine its own goals, if governments use the willingness of parents to organize themselves as a reason for reducing or abandoning existing services. As we have seen, there is pressure on services, and it is very general: in 1980 the Association of County Councils was pressing the government to amend the Chronically Sick and Disabled Persons Act, 1970, in order to make certain statutory obligations of LEAs to assist handicapped people in the community into discretionary powers. This is ironic, as, even now, many LEAs do not fulfil their obligations under this Act. Recent statements by central government also indicate how easily policy makers can use self help to their own advantage. Patrick Jenkin, Secretary of State for Social Services, in an address to the Church of England Children's Society in July 1980, advocated the need to keep handicapped children at home, but he also suggested that it might be undesirable to provide families with too much support: 'Professional help could actually undermine the confidence and competence of ordinary parents.' He said that families needed 'people operating on a self-help basis and making use of resources within the community' (quoted in the *New Statesman*, 20 March 1981). What he said would find many supporters among parents and professionals, but when he said it, and the financial climate in which it was said, are very significant. Could self help become a rationalization for cutting services in the future?

3 *Schools and parents*

3.1 The Warnock Report was in no doubt about the importance that it attached to parental involvement in special education: 'We have insisted throughout our Report that the successful education of children with special educational needs is dependent on the full involvement of their parents; indeed, unless the parents are seen as equal partners in the educational process the purpose of our report will be frustrated' (DES, 1978, p. 150). This is an example of the rhetoric of parental involvement that is everywhere today. Many schools do involve parents, and find it helps them. The staff of an ESN(S) school we know of were surprised by the extra useful information they got when they began to involve parents in their review procedures. But seeing parents as *equal* partners could have quite revolutionary consequences.

Activity 2 What would constitute a equal partnership between parents and teachers? Make a list of the features that occur to you and compare them with other partnerships, such as business partnerships and marriages. Do these comparisons lead you to change your list?

Comment Most partnerships involve two features. First, the partners share certain common goals, and have a say in the selection of these goals. Secondly, partners generally contribute means to achieve those goals. Sometimes the means are identical, as when two entrepreneurs put up so much money each for a business venture; sometimes the means are complementary, as in traditional families where the husband provides the money and the wife sustains the household and cares for the children. Partnerships where neither of these conditions exist may be unjust, oppressive or 'partnerships in name only'. The Warnock Report says not just that there must be a partnership in bringing up handicapped children, but that there must be a partnership *in their education*. In this section we are going to look at how far parents and teachers collectively determine educational goals, and how far they combine to achieve them. And if these two features of a partnership do not exist, or exist only in a weak form, we have to consider what kind of relationship actually exists, and whether it could be otherwise.

Parents and ordinary schools

3.2 It would be difficult indeed to describe the relationship between parents and teachers in most ordinary schools as an educational partnership. Most parents reasonably expect schools to provide them with a service: they expect their children to be educated and in return they pay rates and taxes. It is very unusual for parents to have more than a nominal say in what happens to their child in school. It is open to wealthy families to exercise discretion over which school they send their children to, but even money will not buy parents the privilege of choosing teaching methods and curriculum content. These activities are jealously guarded by most teachers as their professional territory. Indirectly, parents may seek to influence the goals of a school by voting for a political party with certain policies, or by becoming a governor, or a local councillor. Very occasionally parents get sufficiently worried by what a school is doing that they group together to protest about a school. But direct parental involvement in the goals and methods of ordinary schools usually stops at fund-raising, supporting the methods the school has chosen, and giving general encouragement to children over matters such as homework.

3.3 Look, for example, at these notes sent to parents by one primary school, quoted by John Bastiani and his co-workers:

> *Ways in which you can help*
>
> Early bedtimes for your child, including Sunday.
> Spend *time* with your child not just money on him.
> Take an interest in school affairs.
> Read to your child, and hear him read . . .
> Encourage punctuality, good attendance, good manners towards other children and adults.
> Trust school decisions . . .
> We hope that this sort of home-school association will produce happy children who are socially well adjusted and proud of their growing achievements.
> We confidently count on your cooperation.
>
> (Bastiani, 1978)

3.4 The kind of relationship underlying these notes is similar to the relationship that a doctor has with his patient. In order for the professional to operate successfully, the client has to fulfil certain conditions. Whether this is desirable or not, it is the common pattern in school–parent relationships; indeed it is difficult to envisage how it might be otherwise when we have compulsory education for all and a teaching body that thinks of itself as a profession having skills that others do not possess. The skills teachers are given in their training are directed to achieving particular goals, such as teaching children to read. If someone from outside the school system suddenly challenged these goals, that would also be a challenge to teachers' professionalism. Of course, over such matters as whether children ought to learn to read there is usually no disagreement, although some parent–teacher conflicts have come close to this recently, such as that over the Saturday schools that groups of West Indian parents have established to teach their children to read because they believe that schools are not doing so. Over the *way* children are taught there is often much conflict, but since teachers are supposed to possess professional expertise, they are not receptive towards criticisms from non-teachers.

3.5 So most parents do not have much say over how their children are taught once they go to school, but they might have more power to determine the educational goals for their child if they could choose which school they went to. This is a very controversial area that needs extensive treatment for adequate coverage. Here we simply want to point out that educational policy in the late 1970s and early 1980s shifted towards giving parents more choice as to what school their children should go to. Until the 1980 Education Act, legislation on parental choice of school was very loosely expressed. Section 76 of the 1944 Education Act said only that children were to be educated in accordance with their parents' wishes where that was compatible with efficiency and economy. This left matters open for LEAs: some gave no parental choice, others gave as much as they could. Under Section 6 of the 1980 Act, parents have the right to express their preference for a particular school, and LEAs must comply unless this would 'prejudice the provision of efficient education or the efficient use of resources'. Parents whose wishes are not complied with can appeal, in the first place to the local appeals committee, whose decision is binding

on the LEA, and in the second place to the Secretary of State for Education. Whether these provisions will actually increase parental choice remains to be seen. When this unit was being written, they had yet to be implemented.

3.6 In summary, if parents and teachers in ordinary schools *are* partners, the partnership is unequal. They do not have the same amount of control over a child's education. Parents are not free to negotiate with teachers over what happens in the classroom. Most teachers would not think this desirable, but nor do many people think the relationship between homes and schools at present is satisfactory in many instances. There are, and have been for some time, attempts to increase the amount of contact between parents and teachers, particularly in primary schools, and to encourage parents to collaborate with the school in achieving its goals. People advocating these developments have a formidable job; witness two teachers' comments: 'Let us do the teaching and you do the parenting sort of thing'; 'I don't really believe in parents' (quoted in *Contact*, January 1981). But difficulties in collaboration are not all the result of teachers' attitudes: there are parents who are uninterested in their child's education as well.

Parents and special schooling

3.7 Is the situation any different in special education? Are parents accorded more say in the education of their children? Let's look first at the prerequisite for any collaboration: parents and teachers have to be in contact with each other. Some features particular to special education make this difficult. If parents live several miles from the school, then it is much harder for them to drop in for a chat. This problem is made worse when children attend a residential school. Many children are taken to special schools in buses and this also reduces the chances of casual contact between parents and teachers. Take this mother of a severely deaf four year old:

> Once they go to school you don't know what they're doing because very often you don't take them. When I was in A—— I used to take her and fetch her because we were near the school and that was good, and I knew what she'd been doing that day and I could chat to her . . . At B—— she just sailed away in this mini-bus and that was it.
>
> (Gregory, 1976, p. 138)

3.8 Some schools try to ensure regular contact by using home–school notebooks in which teachers and parents can tell each other what has been happening. Susan Gregory found that parents who maintained regular contact in this way very much appreciated it.

3.9 The evidence of how much contact actually takes place between teachers and parents is largely anecdotal. What there is hints that the position is not very different from that in ordinary schools: there are some special schools that welcome parents, that encourage their participation in classroom activities and that involve them in the school's work. There are others where parents are not very welcome. Personal experience suggests that there are rather more schools close to the latter end of the spectrum, such as one described by a project on home–school links:

> During the course of a case-study [of a handicapped child] two major obstacles to cooperation became evident. Firstly the attitudes of the teachers to the parents. The parents were not seen as 'equal partners' with teachers in the education of their child (as suggested by the Warnock Report) but rather as obstacles to the job that teachers were supposed to be doing. Secondly the attitudes of the parents to the teachers. The teachers were regarded by the parents with awe but at the same time with an underlying mistrust perhaps best expressed by the question—'Do they really know what they are doing?'
>
> (*Contact*, January 1981)

3.10 Susan Gregory's parents of deaf children also provided examples of less than close relationships between home and school:

> We had a meeting about parents and teachers. Well the headmaster gave us all a little lecture . . . well about some parents don't seem bothered about what happens, and I said, 'Well, you know, people just don't like going to the school,

interrupting, you know, the classes, and all that,' and he said, 'Well any time anyone comes to the school they're made most welcome' and that. Any time I've ever been I've felt as if I was intruding.

(Gregory, 1976, p. 140)

So special education is not immune from the effects of professional attitudes to parents. In many special schools, just as in ordinary schools, parental links are limited to parents' evenings and notes about such things as swimming costumes.

3.11 Nearly all the examples we have provided so far have been of children who have severe physical, sensory or mental handicaps. But we know from Unit 1/2 that these groups are minorities in special education. The largest groups of children are those categorized as ESN(M) and maladjusted. These children are predominantly working class, and it is frequently argued that they present particular problems as far as home–school links are concerned because many working-class parents are not very interested in education, or are openly hostile to school. Stereotypes are easy to build, but it is certainly true that the problems of co-operation are not always on the school's side. In one residential school for maladjusted children we know, teachers taking children home in the minibus were told not to tell parents what went on at school, since a number of minor incidents had been blown up out of all proportion by some parents and had caused the school considerable trouble. But this kind of problem might not arise if regular and informal contact could be maintained. The next case study shows how parent–teacher relationships can develop under the right conditions.

Reading Now read 'The Wilson family' (Case study 15). Note the factors that helped establish an evidently successful relationship.

Comment The Wilsons were extremely concerned about Andrew's education and development, and took it upon themselves to teach him before he attended school. They became involved in the running of the school: Mrs Wilson became a governor. The school took an interest in Andrew's life outside school, and supported the family during Andrew's stay in hospital.

3.12 One way in which some schools have tried to strengthen links with parents is by the appointment of a member of staff specifically for this purpose: a home–school liaison teacher, or community worker. The next case study describes the work of one such teacher attached to a special school for ESN(M) children.

Reading Now read 'A community worker in a special school' (Case study 25). Try to identify what functions Janet fulfils for the school and for the parents, and whether she actually helps to promote a partnership between the school and parents.

Comment Although one can see that there are many ways in which Janet does promote educational collaboration, by, for example, soothing problems and arranging meetings, she does not escape the conflicting demands of serving the school and serving the parents. There is pressure on her to work for the school, by getting parents to raise money, by taking on tasks such as the organization of the Summer Fayre, and more significantly by representing the school to the parents. She is, for part of the time, an agent of the school. Thus, rather than establishing a youth club in the community, she established one in the school, remote from some children's homes. Her allegiance to the school rather than the parents is strengthened by the fact that there are no parent representatives on the sizeable Management Committee.

3.13 So although home–school liaison teachers can strengthen ties, they can suffer from the same dilemmas of any welfare profession, which were discussed above. Someone who is employed and governed by a statutory agency is accountable to that agency, and pressure exerted by the employer is likely to have a more powerful effect than that exerted by others. Where the welfare agency and its clients agree upon the goals they are working towards, conflicts need not arise. Where there is disagreement, conflicts seem inevitable.

Parental power and special education

3.14 As we said earlier, parents can not only exercise control over education through their contacts with teachers, but also by their choice of schools, and by forming pressure groups to change provision. As you will see in Unit 7, and hear in Radio 2, the power of many groups of parents is very limited. Just as they can be dominated by doctors, they can also be dominated and confused by the professionals who decide on their children's future.

3.15 Until 1981, parent's legal rights in special education have been limited in practice in three main ways. The first appears to be illegal. Section 34(5) of the 1944 Education Act says quite clearly that parents should be able to see any report on which a decision about a child's future is based: 'The advice given with respect to any child by a medical officer in consequence of any such medical examination as aforesaid shall be communicated to the parent of the child.' (The specification of medical officers was because the Act laid down that they should be responsible for assessing children for special education.) However, in practice, LEAs have restricted reports to professionals. In particular, the form which most LEAs now use to summarize what is known about a child and to recommend a placement (the SE4—described in more detail in Unit 5/6) is headed: 'The information on this form must be restricted to those professionally concerned with the child.' Secondly, parents' power has been limited in the same way as other parents' as far as the placement of their child is concerned. LEAs can readily overrule parental preferences, even if the parents are permitted to express them. In practice, most parents have no choice over where their handicapped child is educated, because a range of provision is not generally available. Thirdly, the rights of parents of children with special needs are legally restricted in comparison with those of other parents. In order to ensure attendance at school, the LEA can serve a school attendance order on a parent. This is usually considered a sufficient safeguard to ensure compulsory education. But under the 1944 Act, Section 38(2), parents of children currently attending a special school need to obtain the permission of the local authority if they want to withdraw their child. This effectively limits handicapped children's parents in a way other parents are not.

3.16 It is interesting that in the special education legislation proposed in 1981, parents' rights are more restricted if their child is considered to have special educational needs than if he or she is not. You will recall that the 1980 Act allows parents to express preferences as to the school they want their child to attend. If they do not get their choice they may appeal. Children in need of special educational treatment were excluded from these provisions. Under the 1981 Special Education Bill, parents of children in need of special educational treatment may appeal against a placement decision, but the appeals committee can only refer back a decision to the LEA for reconsideration. For all other children, appeal committee decisions are binding on the LEA.

3.17 Where the law is on their side, parents can be quite a powerful force. This has been recently illustrated by the activities of a parents group in South Oxfordshire. In 1980, Oxfordshire education committee announced that it was planning to close down a unit for 16–19-year-old severely mentally handicapped children attached to a subnormality hospital without offering any alternative places. The parents of these children formed an action group and soon discovered that under the 1944 Education Act LEAs were legally obliged to provide education for all young people up to the age of 19 who requested it. The group appealed for support to Mark Carlisle, the Secretary of State for Education. The DES delayed their response until the group gave them two weeks' notice of high court action. The result of this was a letter from Mark Carlisle to Oxfordshire's chief education officer, Tim Brighouse, confirming that LEAs did indeed have a duty to provide for 16–19 year olds. The LEA then announced that they would open a new further education unit attached to a technical college that would provide for the less severely handicapped children. This proved less than satisfactory for many parents since it still excluded the most severely handicapped children. The group continued to exert pressure and eventually the original unit was reprieved. The campaign had many spin-offs beyond Oxfordshire: the Advisory Centre for Education (ACE) took up the cause and found that at least 60 per cent of LEAs were in breach of their duties to provide education for 16–19 year olds, and many were giving parents misleading advice. One letter unearthed by ACE, from a chief education officer to some parents, said: 'LEAs have discretionary powers to provide education beyond the age of 16' (quoted in *Where*, 1980).

3.18 Here parents successfully fought an LEA over its failure to carry out its duties. However, parents more often find they are trying to force an LEA to do something over which it has discretion. The next case study describes the response of one group of parents to their LEA's policy about educating mentally handicapped children.

Reading Now read 'Parent participation: setting up a special unit in a private school' (Case study 20).

Comment (a) These four children were successfully integrated in normal pre-school facilities, but at school age the local authority's agents put pressure on the parents to send them to schools for severely mentally handicapped children, which the parents resisted. In particular, part of the job of the home teachers appears to be persuading (coercing?) the parents to send their children to a special school. You might compare this with their other functions described earlier.

(b) The LEA was quite within its powers to provide education for these children only in a special school. This group of parents could not exert sufficient pressure on the LEA to make it change its policy. The authority could use the permissive legislation in the 1944 Act to argue that a special unit would not be 'compatible with efficient instruction'.

(c) The opportunity to send the children to a private school occurred by chance, and although the parents were aware that the facilities would be inadequate by comparison with state schools, their views were strong enough to press ahead.

(d) When the unit was threatened with closure through staffing problems and the head mistress's doubts, one parent began to do a great deal to keep the unit afloat.

(e) Establishing the unit was not easy. Both school and parents felt under stress, but nevertheless all parents were pleased that their children had gone there.

(f) For these parents, exercising the kind of control they wanted over their children's education meant stepping outside the statutory education system.

3.19 The rhetoric of partnership remains rhetoric. Parents of handicapped children do not have an equal say in the education system with LEAs, schools or teachers over the kind of education their children receive, no more than any parent does. Deliberate attempts to involve parents in the education of their handicapped children have been concerned instead to get the parents to support those tasks that teachers have selected. Peter Mittler puts this view very clearly:

> In essence this view places the parent in a strategic position with respect to early learning. Parents can be involved in workshops, language programmes, mobility training etc., which require parents to adopt a more structured learning environment than the informal education input which exists in any family.
>
> (Mittler, 1979, p. 47)

3.20 For most parents, involvement in education stops at this level. Very few can exercise power over where their children go to school, and recent legislation seems unlikely to change this. But this only summarizes the current state of affairs. Whether or not the amount of power LEAs, teachers and parents have is the *right* amount, or whether power is unfairly distributed is quite another matter. In Units 7 and 8 you will have more opportunities to think about this issue. We can take our analysis one stage further in the final section of this unit.

4 *Parents and professionals: whose responsibility?*

4.1 Let's summarize the main points in the unit so far. First, having a handicapped child is a continually stressful experience for many parents. The stress is provoked both by the emotional trauma that many mothers and fathers suffer when they find their hopes of a lively, normal child are dashed, and by the continuous practical burden of coping with their child. In the face of these difficulties many families still manage to lead a remarkably normal life and to derive satisfaction and pleasure from their handicapped

Voluntary services such as this minibus are often provided for largely by the efforts of parents themselves. But should parents have more control over statutory services as well?

child. Second, a handicapped child can significantly alter family life. Phases that normally last only a few years can last a life time: ordinary children are dependent for only around 16 years, but handicapped children can be permanently dependent. Parents' opportunities to lead a social life outside the home can be curtailed, as can the opportunities for siblings. Third, a handicapped child brings a family into the public arena. They have to ask for services and are scrutinized; they received the attentions of many more professionals than they would usually expect. Fourth, many families are less than happy with the way they are treated by professionals. They complain of insensitivity, of being undervalued. There are often conflicts between what the professionals foresee for children and what the parents want. Since the professionals are often the gatekeepers to services and resources, their view usually predominates.

4.2 As we said in the introduction, we have deliberately concentrated on a small group of families, those with severely handicapped children, in this unit. This has served to show how difficult the problems can be. But it is vital to remember that many families experience few of the emotional traumas and practical problems we have described. Children with mild learning difficulties can have very ordinary family lives, and the only trauma their parents may suffer is seeing their child failing at school, or being placed in a special school.

4.3 Equally, we have said virtually nothing about parents who don't care for their children. There are many such families, and many such children in special education. The state leaves most families with a great deal of discretion about how they bring up their children, and agencies usually only step in when they suspect children are being abused or when parents cannot or will not look after their children. When statutory agencies should intervene and under what circumstances are very vexed issues. It is often said that agencies intervene too soon and too much and make matters worse. It is also said sometimes that they do not intervene soon enough, as in the case of Maria Colwell that produced a dramatic rethink of social work practice. The problem is to decide the legitimate boundaries of parents' rights and professionals' responsibilities.

4.4 But a lot of the unease about parent–professional relationships with handicapped children is bound up with this problem as well. Many people have claimed that professionals too readily invade parents' territory. In the next reading, Gliedman and Roth argue that this does happen and they put forward their view of why it happens.

Reading Now read 'Parents and professionals', by John Gliedman and William Roth, in the Reader (Reading 4.1).

Comment Gliedman and Roth vigorously state a side of the case that is seldom so forcefully expressed. Here is our summary of their argument:

(a) Because of their special concerns, experts tend to think of handicapped children as 'sick'.

(b) In parent–child relationships with professionals there is an uneven balance: power, authority, credentials, access to scarce resources are on the side of the professional.

(c) Professionals handle conflicts by using their legitimate authority, moral persuasiveness, and 'routinizing' procedures. They appear to prefer parents to be passive, ignorant and irrational, so that the parents are no match for the professionals' claims to power, authority, and influence.

(d) One of the central issues in this unbalanced relationship is the greater need of the client for the professional than the opposite. The careers of professionals depend more on peers' judgements than their clients' appreciation.

(e) Major charges against professionals are that:

(i) they may not have as much expertise as they claim;

(ii) in making suggestions about treatment, placement, and family relationships, they do not always separate their objective judgements as experts from their personal views, but because they are experts, their private views are given weight they may not deserve.

(f) The role of the parent is to receive the wise advice, act upon it and not challenge it, since to do so is to invite being described as sick.

The authors state that professional help is neither negligible nor unimportant. However, they demand a thorough recasting of relationships. This would include:

(a) sorting out legitimate professional areas of expertise from private moral judgements;

(b) avoiding the equation of sickness and handicap;

(c) giving parents an active, participative, consultative role, in which their views and experience are given a valid measure of authority;

(d) encouraging parents to evaluate services;

(e) supporting parents through self-help groups;

(f) encouraging professionals to persuade rather than dictate;

(g) (perhaps the most radical suggestion of all) placing parents at the centre of influence in 'orchestrating' services, although some parents would find this an uncomfortable position if they have incorporated into their thinking the professional's own values.

4.5 The law defines parents' rights, duties and responsibilities. Society adds: 'we recognize you cannot be expected to manage unaided so we make available to you resources which are not available to other families; you may have your house adapted, receive an attendance allowance, free milk, supplementary grants for extended education, you may draw on the family fund, you can stick an orange badge on your car, claim a mobility allowance, claim hospital fares, join a toy library, send your child for special education and join one of the many voluntary societies whose sole purpose is to help you; and if you cannot cope we are, in the last resort, willing to look after your children for you'. Gliedman and Roth suggest that *such services do not come free*. For parents to obtain access to treatment and resources, compliance is no bad tactic but if parents wish to challenge the quality of services offered or to wish to play a constructive (as opposed to a passive) part, they run the risk of being treated as unreasonable or, at worst, 'sick'.

Ideals and reality

Activity 3 In the final part of the unit we want to present you with one writer's view on the kind of relationship between parents and professionals she would like to see. As you read these two 'charters', consider:

(a) what assumptions are made about the kinds of parents whom this advice is meant to help;

(b) which skills a parent needs to acquire to fulfil the parent's charter, and

(c) which of the suggestions you agree or disagree with.

While reading the 'charter for professionals', consider to what extent the charter is being put into practice by any professional groups you know of.

A charter for parents

1 You are the primary helper, monitor, co-ordinator, observer, record keeper and decision maker for your child. Insist that you be treated as such. It is your *right* to understand your child's diagnosis and the reasons for treatment recommendations and for educational placement. No changes in his treatment or educational placement should take place without previous consultation with you.

2 Your success in getting as well informed as you will need to be to monitor your child's progress depends on your ability to work with the people who work with your child. You may encounter resistance to the idea of including you in the various diagnostic and decision-making processes. The way you handle that resistance is important. Your best tool is not the angry approach. Some of your job will include the gentler art of persuasion. Stay confident and cool about your own abilities and intuitions. You know your child better than anyone else could. You are, obviously, a vital member of the team of experts.

3 Try to find, from among the many people whom you see, a person who can help you co-ordinate the various diagnostic visits and results. Pick the person with whom you have the best relationship, someone who understands your role as the principal monitor of your child's progress throughout life and who will help you become a good one.

4 Learn to keep records. As soon as you know that you have a child with a problem, start a notebook. Make entries of names, addresses, phone numbers, dates of visits, the persons present during the visits, and as much of what was said as you can remember. Record the questions you asked and the answers you received. Record any recommendations made. Make records of phone calls too; include the dates, the purpose, the result. It is best to make important requests by letter. Keep a copy for your notebook. Such documentation for every step of your efforts to get your child the service he needs can be the evidence which finally persuades a program director to *give* him what he needs. Without concise records of whom you spoke to, when you spoke to him, what he promised, how long you waited between the request and the response, you will be handicapped. No one can ever be held accountable for conversations or meetings with persons whose names and titles you do not remember, on dates you cannot recall, about topics which you cannot clearly discuss.

5 Make sure that you understand the terminology used by the professional. Ask him to translate his terms into lay language. Ask him to give examples of what he means. Do not leave his office until you are sure you understand what he has said so well that you can carry the information to your child's teacher, for instance, and explain it to her in a clear, understandable language. (Write down the professional terms too. Knowing them might come in handy some time.)

6 Ask for copies of your child's records. You probably will not get them, but you *could* ask that a tape recording be made of any 'interpretive' conference. It is very hard to remember what was said in such conferences.

7 Read. Learn as much as you can about your child's problem. But do not swallow whole what you read. Books are like people. They might be offering only one side of the story.

8 Talk freely and openly with as many professionals as you can. Talk with other parents. Join a parent organization. By talking with people who 'have been through it already', you can gain a perspective on your particular problems. Besides, you will receive moral support and will not feel quite so alone. Get information from parent organizations about services available, about their quality. But bear in mind that a particular program might not help your child even though it has proved helpful for another child. Visit programs if you have the time and energy to do so. There is no substitute for firsthand views.

9 Stay in close touch with your child's teacher. Make sure you know what she is doing in the classroom so that, with her help, you can follow through at home. Share what you have read with her. Ask her for advice and suggestions. Get across the idea that the two of you are a team, working for the same goals. Make your child a part of that team whenever possible. He might have some great ideas.

10 Listen to your child. It is *his* point of view that he is giving you, and on that he is an expert.

11 Work hard at living the idea that differentness is just fine—not bad. Your child will learn most from your example. Help him to think of problems as things that can be solved if people work at them together.

A charter for professionals

1 Have the parent(s) involved every step of the way. The dialogue established may be the most important thing you accomplish. If the parent's presence is an obstacle to testing because the child will not co-operate in his presence, the set-up should include a complete review of the testing procedure with the parents. (Remote video viewing or one-way windows are great if you are richly endowed.)

2 Make a realistic management plan part and parcel of the assessment outcome. Give the parents suggestions for how to live with the problem on a day-to-day basis, with the needs of the child, the capacities of the family, and the resources of the community all considered. Let the parents know that you will suggest modifications if any aspect of the management plan does not work.

3 Inform yourself about community resources. Give the parents advice on how to go about getting what they need. Steer them to the local parent organization.

4 Wherever possible, make the parent a team member in the actual diagnostic, treatment, or educational procedures. It will give you a chance to observe how the parent and the child interact.

5 Write your reports in clear, understandable jargon-free language. Professional terminology is a useful shortcut for your own note-taking, and you can always use it to communicate with others of your discipline. But in situations involving the parent, it operates as an obstacle to understanding. Keep in mind that it is the parent who must live with the child, help him along, shop for services to meet his needs, support his ego, give him guidance. You cannot be there to do it for him. So the parent *must* be as well informed as you can make him. Information that he does not understand is not useful to him. The goal is to 'produce' a parent who understands his child well enough to help him handle his problems as he grows up.

6 Give copies of the reports to parents. They will need them to digest and understand the information in them; to share the information with other people close to the child; and to avoid the weeks or months of record-gathering which every application to a new program in the future will otherwise entail.

7 Be sure the parent understands that there is no such thing as a one-shot, final, and unchanging diagnosis. Make sure he understands that whatever label you give his child (if a label must be given) is merely a device for communicating and one which may have all kinds of repercussions, many of them undesirable. Make sure he understands that it says very little about the child at present and even less about the child of the future. Caution him about using that label to 'explain' his child's condition to other people.

8 Help the parent to think of life with this child in the same terms as life with his other children. It is an ongoing, problem-solving process. Assure him that he is capable of that problem solving and that you will be there to help him with it.

9 Be sure that he understands his child's abilities and assets as well as his disabilities and deficiencies. What the child *can* do is far more important than what he cannot do, and the parent's goal thereafter is to look for new abilities and to welcome them with joy when they appear. Urge him to be honest and plain speaking with his child. Tell him that the most important job he has is to respect his child, as well as love him, and to help him 'feel good about himself'. Tell him that blame, either self-blame or blame of the child, has no part in the scene. *It is no one's fault.*

10 Warn the parent about service insufficiencies. Equip him with advice on how to make his way through the system of 'helping' services. Warn him that they are not always helpful. Tell him that his child has a *right* to services. Tell him to insist on being a part of any decision making done about his child.

11 Explain to him that some people with whom he talks (teachers, doctors, professionals of any kind, other parents) may dwell on negatives. Help train the parent not only to think in positives but to teach the other people important in his child's life to think in positives.

(Gorham *et al.*, 1976, pp. 183–6)

Reading Now read 'Professional 'help': the Taylor family' (Case study 12). This family is quite unlike any of the other families described in the unit. It has many problems. As you read it, consider these questions:

(a) Has the massive professional involvement in this family helped them in any way?

(b) Do you think that the 'charters' described above would help in any way to improve the professional involvement with this family?

(c) Could these charters actually be implemented in this situation?

(d) What would be your solution to these difficulties?

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Tables

Tables 1 and 2 from Gregory, S. (1976) *op. cit.*

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Unit 1/2 Special biographies	Unit 10 National perspectives
Unit 3 Family views	Unit 11 Biology and handicap
Unit 4 Education for adult life?	Unit 12 Psychology and special education
Unit 5/6 A special curriculum?	Unit 13 Handicap is social
Unit 7 The professionals	Unit 14 Eradicating handicap
Unit 8 The powers that be	Unit 15 Research in special education
Unit 9 Origins	Unit 16 An alternative system: a special imagination

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